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ABSTRACT

This "gray paper" addresses the concerns of older women regarding their control over death and dying. It is based on the observation that older women are devalued by society on account of both their age and gender, and hence are likely to be impoverished and vulnerable as they approach death. The paper begins by examining the legal, ethical, and economic consequences of the medical profession's control over the right to die. A review follows of court cases which have established the legal principle that a competent terminally ill patient can refuse or terminate life-sustaining treatment at any time. "Living Wills" and other advance directives to help women stay in control of their bodies are then discussed, along with the conflicts and contradictions inherent in the subject of death and dying--specifically, the danger of "right to die" directives degenerating into a license for euthanasia. The paper concludes with principles to help women navigate the complex legal, medical, and emotional minefield of death and dying, and with recommendations for personal planning, legislative support, public education, and new alternatives for terminal care. A list of publications and organizations is included. (TE)

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GRAY PAPER

Death and Dying: Staying in Control To the End of Our Lives

OLDER WOMEN'S LEAGUE

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Death and Dying:
Staying in Control To the End of Our Lives

Introduction

Death and dying are very much older women's concerns. While all older people (and young ones too) are affected, women have a special stake. For one thing, we are handmaidens of death. The last face a dying person is likely to see on earth will probably be a woman's. In the hospital it will be the nurse or nurse's aide taking the vital signs; in a nursing home it will be an attendant; both are likely to be women. At home in the arms of one's family, there will probably be a woman at the bedside, since 85% of surviving spouses and the majority of family caregivers are women. As handmaidens to the dying, women receive low pay, or no pay, for the task of helping someone die. Their caring work is invisible and their status low.

Because women are more frequently survivors of a marriage, they more frequently die without a spouse in attendance, or end their lives in an institution for the aged or disabled, usually a nursing home. In 1980, women outnumbered men three to one among the 1.2 million persons residing in such institutions. Nearly 40% of the women had been in homes for the aged for at least five years.[1] For these reasons, policies related to care at the end of life are overwhelmingly a woman's concern.

Further, policy decisions may be affected by gender differences, which are inexorably linked to economic considerations. Since so many woman end their lives in or near poverty, their options are greatly reduced. The circumstances of an older woman's death may be determined by what medical treatment public funds will buy. How society values poor older persons, predominantly women, is an important factor. Considerable attention has been given to demographic shifts--particularly the anticipated increase in the number of dependent elders, compared with the "productive" age groups in coming years. In some cases what are called "demographic shifts" are euphemisms for too many old people, mostly female. Because women live longer, are more likely to be poor and end their days in institutions, and primarily because aged women are among the fastest growing segments of the population, all discussion concerned with the end of our lives is particularly relevant to midlife and older women. We ignore it at our peril.

Finally, women need to be concerned because we older women of today have been socialized to accommodate ourselves to the needs of others. This is a virtue which should be more equitably spread throughout society. We are more vulnerable when we sacrifice our own desires for the good of our families, and are not immune to social pressures to "move aside" in the interests of younger people. Such pressures to yield to the claims of others should be looked at carefully.

But facing our own mortality is not easy, although we will all die. We are all terminal cases. Death is part of the life course, but it is the part

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[1] Most of this paper was written by Tish Sommers, with contributions from Bernard Lo, Stephen Blum, Laurie Shields, Donna Ambrogi, Vicki Jaycox, Fran Leonard and Alice Quinlan. Editing after Sommer's death was carried out by Alice Quinlan and Vicki Jaycox, with contributions from Paul Kerschner, A.J. Levinson, and David Nee.

most of us would prefer to avoid thinking about as long as possible. Through the experience of those close to us, however, we are forced to consider our own mortality as we grow older. Technological advances in medicine make us think about our own vulnerability and the circumstances we may face at the end of our lives. What if we are no longer able to make life or death decisions in our own behalf? What if we are kept alive by mechanical means long after our minds and our spirits have succumbed? What if we lose control of what happens to us?

The purpose of this Gray Paper is:
-- to examine the medical profession's control over the right to die,
-- to analyze life sustaining treatment and the law,
-- to look at "living wills" and other advance directives that can help us stay in control of our bodies to the end of our days,
-- to point out conflicts and contradictions inherent in the subject,
-- to suggest principles to help us maneuver within the minefield of these complicated questions, and
-- to offer some direction for action.

Here we present a beginning and not an end. The process of dialogue helps clarify our own thinking and contributes to the national debate on these questions, which inevitably will grow louder. By so doing, we can contribute to the development of social policy based on humane and realistic premises.

The Medical Profession and the Right to Die

Medical technological advances have dramatically changed the time, the place and the conditions of dying. A study by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research points out that these new developments have made death more a matter of deliberate decision.[2] For almost any life-threatening condition, some intervention can now delay the moment of death, but not its inevitability. States the Commission's report, "Matters once the province of fate have now become a matter of human choice, a development that has profound ethical and legal implications."[3] In the past, most people died at home surrounded by family members. Now, death is more likely to occur in a hospital, even if the patient had been living in a nursing home. The "human choice" is usually in the hands of the physician or hospital personnel. In the case of the clearly incompetent patient, such as a person in a coma, the question of "right" becomes even more murky. This is the area around which current controversies center.

In a variety of cases, the courts are reaffirming the right of terminally ill patients to refuse medical life support when the patient is competent to make that decision. But what does "competence" mean? A person's capacity to make decisions is a relative matter. According to one expert, "What is important, both legally and ethically, is the patient's ability to understand the particular treatment choice presented, to make a decision regarding that choice and to communicate that decision."[4] While a competent patient has the right to refuse medical treatment, a working definition of competence may be the willingness to agree to whatever treatment the doctor orders. For example, it is not uncommon for doctors,

faced with terminal patients who refuse a treatment saying they want to die, to suggest the services of a psychiatrist.

Doctors and nurses have always dealt with dying, but not until the present technical advances have they had so much power and responsibility to control how long life lasts. As a result, there is growing recognition that there needs to be a new set of ethics--and practices--to match the new medical capabilities. Decisions can be excruciating ones for doctors, nurses, family members and patients. Where do you set the limits? At what point do you stop prolonging life, when the alternative is so final? How much suffering is "worth it" to stay alive? Medical professionals are taught that death is the enemy and life should be prolonged at all costs. Now the situation has changed. Should dying be prolonged indefinitely when there is no possibility of recovery?

Underlying all ethical considerations are economic consequences -- for doctors, hospitals, patients, families, and most of all for the public (the taxpayer). As economic advantage or disadvantage shifts, moral rationales may accommodate that change. For example, a sizable percentage of persons end their days with Medicare picking up the bill. In fact, much has been made of the high cost of dying. With pressure mounting to reduce medical bills paid with public funds, life support for patients with terminal illnesses is being questioned. In the past, hospitals were reimbursed for each service, treatment, test and the full time patients were hospitalized. But now Medicare pays hospitals under a prospective payment system using Diagnosis Related Groups (DRG's), which means a set maximum is paid for any particular illness or treatment. Thus the economic incentive in many cases will shift from keeping a person alive to allowing the patient to die or at least to remove the patient from the hospital. As a result of policy shifts, there is danger that for economic reasons life-sustaining treatment will be withheld from patients who want it.

Public opinion on the right of terminally ill patients to say "no more" is shifting. According to recent Gallup and Harris polls, eight out of ten persons believe that a terminally ill patient should be able to ask doctors to stop life-supporting medical treatments.[5] The Gallup poll asked: "The New Jersey Supreme Court has recently ruled that all life-sustaining medical treatment may be withheld or withdrawn from terminally ill patients, provided that is what the patients want or would want if they were able to express their wishes. Would you like to see such a ruling in the state in which you live, or not?" Overall, 81% favored that statement, 13% were opposed, and 6% were undecided.

The Harris poll asked the following: "All doctors take an oath saying they will maintain, restore and prolong human life in their treatment of patients. It is now argued by some people that in many cases people with terminal diseases, those which can only end in death, have their lives prolonged unnecessarily, making them endure much pain and suffering for no real reason. Do you think a patient with a terminal disease ought to be able to tell his doctor to let him die rather than to extend his life when

no cure is in sight, or do you think this is wrong?" In 1973 when the question was first asked, 62% thought a patient should have this right; in 1985, 85% agreed with the statement.

In 1985, a more controversial question followed. Harris asked: "Do you think the patient who is terminally ill, with no cure in sight, ought to have the right to tell his doctor to put him out of his misery or do you think this is wrong?" A surprising 61% said the patient should have such a right and 36% said it was wrong. In the 1973 poll, 53% were in favor, 37% were opposed, and 10% were undecided.

Public opinion toward the medical profession has also shifted in the past decade or so. The advances in medicine and public health in the first half of this century raised doctors to the position of demigods. That high esteem has eroded in the past decades resulting in tremendous increases in malpractice suits. This litigation has ironically tightened the grip of medical facilities and practitioners on the process of dying. Fear of suits from unhappy relatives pushes physicians and hospitals to "heroic measures," even when death is inevitable.

Medical professionals feel that they are on the spot. If they do everything that can be done to keep a patient alive, they are under attack. In the past, the "family" and the physician made these life and death decisions. But without legal assurances of immunity from civil or criminal liability, medical staffs are increasingly unwilling to follow the informal tradition of complying with the instructions of the family. How can doctors be relieved of this dilemma? How can individuals maintain personal autonomy to the end of their lives?

Life-Sustaining Treatment and the Law

There is an underlying legal principle that a competent patient can refuse or terminate any medical care at any time (with rare exceptions), even if the immediate consequence is death. But legal processes are not speedy and they are expensive. A "living will," a document which clearly states in advance what treatment a patient does or does not want in the event of a terminal condition, may or may not be adhered to when the chips are down. With or without a living will, one can win a case in court--after a year or two--but lose it on the hospital bed.

A dramatic example of the dilemma of slow action by the courts is the Conroy case in New Jersey.[6] In this case, Claire Conroy, an 84-year old patient in a nursing home, who was declared incompetent to make decisions on her treatment, was kept alive by a nasal feeding tube to her stomach. The institution and the doctor refused to consider her terminal, and would not remove the tube. Her guardian, a nephew, sued for an order requiring the tube to be removed, arguing that this would have been her desire. The trial court decided to permit removal of the tube, arguing that Ms. Conroy's life had become impossibly and permanently burdensome, thus justifying removal. The case was appealed, during which time Ms. Conroy died with the nasogastric tube in place. Nevertheless, the appellate court decided to resolve the issues since this type of case was not uncommon, and such cases were not being resolved in court because the patients died during litigation.

The appellate court reversed the lower court, ruling that removal of the tube would be counter to established principles protecting patients from being harmed by medical personnel. The court ruled that depriving a patient of such a basic necessity of life as food would hasten death, rather than allow the illness to take its natural course; her death, which would follow removal of the tube, would therefore be criminal homicide. The case was appealed to the New Jersey Supreme Court.

The New Jersey Supreme Court reversed the appellate decision, and in the process produced a ruling which commented on many of the most difficult issues involved with the right to die. It held that life-supporting treatment may be withheld or withdrawn from an incompetent patient when it is clear that the particular patient would have refused the treatment under the circumstances involved. It strongly reaffirmed the personal right to control one's own life. "The question is not what a reasonable or average person would have chosen to do under the circumstances but what the particular patient would have done, if able to choose for himself."[7] The court set aside arguments about the "quality of life" and "value to society" as justifications for withholding treatment. It made no distinction between "ordinary" and "extraordinary" (heroic) measures to maintain life, or between passive (failing to administer life-extending procedures) and active measures (such as removing a respirator). The right of a person to control his or her own body was seen as the overriding principle. The case is hailed as a milestone by those working for the right to die. In New Jersey at least, the court has taken a position in line with public opinion as expressed in the polls.

In another example, a California Court of Appeals ruled unanimously that William F. Bartling's refusal to accept treatment was "a constitutionally guaranteed right which must not be abridged."[8] Bartling, age 70, had entered a hospital with five potentially fatal illnesses in April, 1985. In June he filed a $10 million lawsuit against the hospital for its refusal to disconnect him from the respirator. Bartling had tried several times to remove ventilator tubes, and hospital officials put restraints on his wrists. The hospital administration disagreed that Bartling was terminally ill, and refused to honor his wishes. Bartling eventually won the case, but he died in the course of litigation with the tube still in.

The Bartling case points out the gap between legal theory and medical practice. The courts may back up a living will, but hospitals and doctors may be reluctant to go along, pointing to other lawsuits. For example, in the recent Barber case in California,[9] as a result of a complaint brought by a nurse, two Kaiser Hospital doctors (Neil Barber and Robert Nedjl) were charged with murder for removing the feeding tube from an irreversibly comatose patient. The patient, Clarence Herbert, did not have a living will, but had previously made clear to his wife his desire not to have life-prolonging treatment when terminally ill. While a court of appeals ultimately dismissed charges, the danger of suits alleging civil and criminal liability has a chilling effect on hospitals and doctors.

For the medical profession, there are ordinarily few liabilities for continuing to treat a patient, but there may be grave dangers in stopping

treatment. To protect themselves from lawsuits, hospitals seek legal advice; since there are still many gray areas in the law, and the U.S. Supreme Court has not yet ruled on the subject, hospital lawyers tend to urge caution when it comes to withdrawing life support systems.

In the past, when doctors, patients and families were on closer terms and medical technology was not as advanced, care was often terminated informally when death was imminent even though legal guidelines were unclear or nonexistent. Efforts to cure were replaced by solace and comfort. Lawsuits were rare and dying persons could not be kept alive very long anyway. At the present time there may be a growing consensus among the public about letting patients die by withdrawal of life supports, but the reality in most hospitals is a very cautious approach to all such matters.

The presumption on the part of the medical profession is to spare no effort to keep a patient alive. What if one relative favors removal of the life support system and another opposes?This is not an unusual situation. Doctors are afraid of being caught in the middle of family disagreements on whether to maintain life support systems. If there is agreement between doctors and all family members that everything has been done that can be done, and particularly if the patient has expressed his or her wishes in advance, efforts to prolong life may be halted. However, because institutions of all kinds tend to be self-protective, a person has a far better chance of being allowed to die in a natural way at home rather than in a hospital.

Since the public and the courts seem to be moving toward the position that it is everyone's right to refuse treatment of any kind[10] and since it is in the interest of the medical profession to have these questions clarified, the problem becomes: how can a person's wishes be expressed in advance, in such a manner that they will be legally binding on all concerned? We will consider options for that in the next section.

Related to this problem is one of "informed consent"--that is, how can the patient be provided with enough information on both the benefits and possible negative consequences of any procedure to make an informed decision. The Conroy case defined it as follows: "The doctrine of informed consent presupposes that the patient has the information necessary to evaluate the risks and benefits of all the available options and is competent to do so.... In general, it is the doctor's role to provide the necessary medical facts and the patient's role to make the subjective treatment decision based on his/her understanding of those facts."[11] The right of informed consent thus encompasses the right to informed refusal, the ruling states, and this right is embraced within the common law right to self-determination.

Unfortunately, doctors can phrase options and present their own advice in such a manner that the uninformed patient feels helpless in making a contrary decision. Most people are both awed and intimidated by doctors, and older women even more so. For example, it is very difficult for a woman with advanced cancer to weigh the benefits against the negative side effects of chemotherapy when the oncologist (with few exceptions, male) is telling

her of survival rate percentages of the recommended therapy. She has no way to judge how accurate these percentages are or to know how she individually will respond to the treatment, or even how to compensate for the physician's bias toward his own discipline. While she has been informed in a professionally acceptable manner, she must make a decision with life or death consequences for herself, which is very difficult to do. Critically-ill persons need access to a "medical ombudsman," who can help them make informed decisions and weigh the pros and cons of recommended procedures.

Living Wills and Durable Powers of Attorney

The right to refuse treatment is a corollary to informed consent, but what if a person is critically ill, severely injured, impaired by drugs or in a comatose state? These are the situations when life and death decisions are most frequently made. Who speaks for the patient?

Living wills were designed as a tool to state in advance one's personal wishes on life sustaining treatment when one is no longer able to make decisions and death is imminent. In the wake of the national publicity on the Karen Ann Quinlan case, millions of these living wills have been distributed and probably millions of persons have made declarations of their wishes in one form or another. Organizations like Concern for Dying and the Society for the Right to Die have taken the lead in this effort.[12]

Legislation to back up such "advanced directives" has spread rapidly. At the time of this writing, 36 states and the District of Columbia have passed such laws and other states are considering them. The purpose of this legislation is twofold: to permit persons to prepare in advance a legally recognized document stating their wishes, and to protect physicians from liability if they follow it.

In the past few years, opposition to such legislation has softened. The President's Commission for the Study of Ethical Problems in Medicine recognized the autonomy of patients and the need for individuals to state their wishes in advance. Further, the Commission recommended that state courts and legislatures should consider making provision for advance directives through which people designate others to make decisions on their behalf or give instructions about their care.[13]

One problem with living wills is that they usually apply only in cases of terminal illness. Another difficulty is that many contain ambiguous language. In effect they say, "If I am going to die anyway, don't extend my life by extraordinary means. Just provide supportive care so I can die in peace and dignity."[14]

Is artificial feeding by nasogastric tube or intravenous infusion an extraordinary measure or does it constitute supportive care? In several states, natural death acts specify that artificial forms of nourishment may not be withheld, but must be provided. In addition, in most cases living wills apply only to refusal of treatment, not to removal of life-sustaining procedures.

All statutes with the exception of Arkansas contain definitions for "life-sustaining procedure." The one used in California's Natural Death Act is typical:

> "Life-sustaining procedure" means any medical procedure or intervention which utilizes mechanical or other artificial means to sustain, restore or supplant a vital function which, when applied to a qualified patient, would serve only to artificially prolong the moment of death and where, in the judgment of the attending physican, death is imminent whether or not such procedures are utilized. "Life-sustaining procedure" shall not include the administration of medication or the performance of any medical procedure deemed necessary to alleviate pain.[15]

There are many gray areas here which the courts have not yet resolved, such as the definition of "terminal condition":

> ...an incurable condition caused by injury or illness which, regardless of the application of life-sustaining procedures, would within reasonable medical judgment produce death, and where the application of life-sustaining procedures serve only to postpone the moment of death of the patient."[16]

What about the person who is suffering from a breakdown of many physical functions, but is not considered terminal by the physician? Because it is so difficult to anticipate circumstances at the end of life, it is hard for anyone to write in advance what they would like done or not done except in a general way. It is in applying the specifics that the problems arise.

A person with a living will drawn up to satisfy the requirements of one state may become ill in another state with different stipulations. For example, the District of Columbia statute specifies in what form the declaration must be made. Texas requires that its model be followed exactly. Witnesses to the declaration are required in most cases, but states vary on who may not be a witness, such as an heir. In three states (California, Idaho, and Oklahoma) the declaration is legally binding only if executed after the person has been diagnosed as having a terminal illness; in four states (California, Georgia, Idaho, and Wisconsin) the living will is valid for a limited period, varying from five to seven years.[17]

These differences have led to the development of a model draft law designed by the National Conference of Commissioners of Uniform State Laws. State legislatures may give this model serious consideration.[18] However, like most models developed by such a body, the bill is a compromise document with both strengths and weaknesses.

Another way to keep control of those final days in the event of losing decision-making power is the durable power of attorney, which is valid in all states, but not the District of Columbia. Such a document permits a person to designate a surrogate, not necessarily a lawyer, who is empowered to make decisions for the signer. This principle is now well established in law. The term "durable" means that it remains in force even if the signer becomes incompetent, as when in a coma. Two states (California and

Pennsylvania) have passed legislation for such a durable power of attorney **specifically** for health care. However, other states permit the normal durable power of attorney form to be used to designate a proxy for health care decision-making; some of them have specific requirements for notarization, filing and, in a few states, court approval. The person one would choose to make financial decisions might not be the same person best suited to make difficult life-support decisions. Legally designating a person who is thoroughly cognizant of one's wishes as the individual to make those tough decisions provides important back-up when there is doubt in the minds of medical practitioners.

One problem encountered by some very sick patients is being asked to consent to some procedure. Even if the person has prepared a living will, a doctor--not necessarily the one who knows the case best--may confront the patient with an either/or choice of alternatives: "You can either have this operation or you will die; which do you want?" Unless there is someone standing in with the patient, helping him or her think through the decision, the patient may acquiesce, but this is hardly informed consent. A surrogate can act as an ombudsman to help the patient make his or her wishes known. How to implement those wishes to assure autonomy for the dying patient will be considered later.

Conflicts and contradictions related to death and dying

If public opinion is marching forward toward individual determination on whether to accept life-sustaining treatment, and state legislatures are responding to this sentiment by passing "right to die" or "death with dignity" legislation, and the idea of expressing one's wishes ahead of time in living wills is gaining favor, and courts--however slowly--are upholding the right of individuals to make their own medical decisions, where is the dilemma?

Unfortunately it's not that simple, because we are talking about life and death. In fact, the subject is a minefield of contradictory concepts, of dangers real and imagined, of hidden economic interests and pressures, and of long-held beliefs "out of sync" with medical technology. While there is a great deal of hope for a more enlightened way of taking control of our own last days, there is also the underlying danger of things getting out of control. The fear is this: a government that sanctions an "easier death" today may require it tomorrow.

Those who oppose even legislation authorizing advance directives like living wills talk about the "slippery slope." This argument cautions against taking a first step which may be benign, but which will lead to acceptance of less desirable actions. "Take the first step and you can't stop, but will slide down to the very bottom," the argument goes. In this context it is argued that human life must be protected at all costs, or something similar to Nazi prison camps could be the end product.

Of course any well-justified action can lead to further actions which are unjustified. But to demand inaction, more is required than that. As the report of the President's Commission explained:

> [I]t must be shown that pressures to allow the unjustified action will become so strong, once the initial step is taken, that the further steps are likely to occur. Since such evidence is commonly quite limited, slippery slope arguments are themselves subject to abuse in social and legal policy debate. Obviously slippery slope arguments must be very carefully employed lest they serve merely as an unthinking defense of the status quo.[18]

The target of those who raise the "slippery slope" argument is **euthanasia.** The word literally means "a good death", but the Nazi experience has sensitized the public to the dangers of shifting responsibility for decisions on life and death matters from individuals to the state. Yet the Harris poll concluded that "the concept of euthanasia now has substantial support from the American public..."[19] When euthanasia is defined as Harris does in the poll, it seems clear that the public is saying that a prolonged dying process does not preserve life at all, but forcibly puts people in limbo between life and death. Most persons would like to protect themselves from that fate.

Many people make a distinction between "passive conduct" (doing nothing, like not administering CPR when that could prolong life) and "active conduct" (withdrawing a nasogastric tube, as in the Conroy case). Recent surveys suggest that a majority of practicing physicians approve of passive conduct to end life and believe it is being practiced by many members of the profession. However, the distinction between doing nothing and taking action runs into trouble in a modern hospital. If an unconscious patient is brought into an emergency room, should an intraveneous tube be attached when removing it later might cause conflicts if the patient is dying? The Conroy ruling dealt with the difficulties of the distinction in this way:

> The line between active and passive conduct in the context of medical decisions is far too nebulous to constitute a principled basis for decision making. Whether necessary treatment is withheld at the outset or withdrawn later on, the consequence--the patient's death--is the same....[20]

Too sharp a distinction between active and passive conduct might discourage families and doctors from attempting certain kinds of care and thereby allow the patient to die, the New Jersey Court said.

The problem becomes murkier when the subject is suicide. Should persons who are terminally ill, such as advanced cancer patients, be permitted to shorten their own lives? Is that part of self-determination? Most religious traditions and strong social taboos oppose suicide, although attitudes are changing in the case of terminally ill persons. Is it suicide to refuse treatment if the result of refusal is death, or is it letting the disease take its course? Most living will laws specifically state that refusing treatment which would prolong the life of a terminally ill patient does not constitute suicide. The Conroy decision stated:

> Declining life-sustaining medical treatment may not properly be viewed as an attempt to commit suicide. Refusing medical intervention merely

> allows the disease to take its natural course; if death were eventually to occur, it would be the result primarily of the underlying disease and not the result of a self-inflicted injury.[21]

What about the terminal cancer patient who hastens the process? To refuse treatment is one thing; to take an overdose of pills is another, even though the underlying cause of death is the cancer. Although the person attempting suicide would not be prosecuted, anyone discovered assisting in that act might well be prosecuted.

There are those who take a different view, most notably in this country, the Hemlock Society.[22] This organization distinguishes between "rational suicide" (called the option of self-deliverance--ending one's life for good and valid reasons), and suicide which is caused by a rejection of life because of emotional disturbance. The Hemlock Society not only promotes the right of mature terminally ill persons to determine for themselves the time, place and circumstances of their death, but also calls for decriminalization of assistance to a person who has made that decision. The Netherlands is the only country which has taken this step, permitting physicians, with carefully prescribed precautions, to administer a lethal dose to a terminal patient who requests it.

Taking a contrary view are most hospice organizations, which seek to mitigate the distress of dying through control of pain and to provide emotional support both for patients and their families. Hospices believe that suicide is not necessary because pain can be controlled through their methods, and that suicide causes greater distress for the survivors than a natural death. The latter view brings into focus the issue of the extent to which dying patients have an obligation to their survivors. Many argue that the dying person's primary obligation is not to others. Others question whether pain can really be controlled with drugs that are currently legal in the U.S. Among them is the National Committee on the Treatment of Intractable Pain, which promotes the medicinal use of heroin for terminally ill cancer patients.[23] Heroin is widely used outside the United States, and is claimed to be the most effective pain control medication existing.

In general, the hospice focus is on the quality of life in its terminal phase; it accepts death and helps dying persons cope with the process rather than fight against it. The hospice movement is based upon the philosophy that dying has become highly "medicalized" and that many terminal patients need a different kind of care. Hospice philosophy supports the wishes of the patient and family, and tries to make the process of dying as free of stress as possible. Hospices which primarily provide nursing care use interdisciplinary teams of professionals to offer support in whatever way they can.

The first hospice program in this country started in 1974 and there are now about 1,600 programs. Some are based in a person's own home and may require that there be a family caregiver available. Others provide in-patient beds and still others are limited to case management, referring patients to whatever community services are available. Most hospice participants are terminally ill cancer patients.

From the dying patient's point of view, hospices provide support for whatever that person needs to do to make the passing less traumatic. The subject of death is not avoided. The whole family unit is seen as needing help, rather than just the patient.

As a result of advocacy for public funding of hospice care, coverage under Medicare was permitted in the Tax Equity and Fiscal Responsibility Act of 1982. Unfortunately, in the climate of fiscal stinginess for human service programs, Congress authorized a three-year trial Medicare benefit to see if hospices provided a cheaper alternative to existing models.

In drawing up the regulations for Medicare certification, the Dept. of Health and Human Services added significant limitations and restrictions, which distort the basic hospice principles. As a result, by March 1985, only 165 hospice programs had received Medicare certification. Most were waiting to see if such certification would survive the ambivalence of Congress and the Administration to extend the program past October, 1986. The primary advantage of such certification is expanded patient benefits. In March 1986, Congress passed legislation making the hospice benefit a permanent part of the Medicare program and granting a modest increase in reimbursement rates.[24]

Overall, discussion of these complex issues frequently divides people into two groups: those who would increase the options of dying persons to determine for themselves how, when and where they would end their days; and those who are fearful of the consequences that any loosening of the ground rules would cause. [25] Those who vehemently oppose liberalization of law and custom at the end of life use the slippery slope argument: "Allow persons to decide the manner of their own death and soon society will have no controls; people will be putting their grandmothers out of the way." Such a line of reasoning, as the Conroy court pointed out, serves primarily as an unthinking defense of the status quo.

There are certainly legitimate areas for concern, and many thoughtful persons caution against moving too fast. Will, indeed, the government that sanctions an easier, swifter death today, require it tomorrow? Persons who fear this consequence point to the economic pressures on and from government to cut health care costs at times of high budget deficits, especially in care for the frail elderly population. Here is a negative projection of what might happen:

Suppose, in the next few years, the economic situation worsens. The arms race is speeded up. Inflation again gets out of hand. With the presumed goal of fighting government costs, all "entitlements" are re-examined -- Social Security, Medicare, Medicaid and the like. Hard-fought benefits are nibbled away. There is a growing backlash against elders, broadly supported by the media, which leads to even further curtailments, especially medical costs, which have not been contained. Old people are now considered too expensive, too great a burden on the public purse: "They're getting more than their share.... They're not productive and most of them are quite well off anyway.... They've had their turn and now it's ours."

Now imagine that these negative attitudes breed an inevitable reaction: further separation of the older population from the issues of society and from concern about the future. For the better-off aging population, there are well policed retirement communities, but for the majority, especially widows and minority elders, the situation is grim indeed. Individual problems are no longer viewed as reflections of social ills, but are attributed to poor planning and bad luck.[26] As social responsibility lessens, there is an ever growing population of young and old who are dependent, alienated, powerless and poor, who take their frustration and rage out on each other. The intergenerational cold war is well entrenched.

Limits are placed on everything except goods and services destined for war. The large population of the aged is seen as a handicap. At last--a pharmaceutical breakthrough: a death-with-dignity pill which causes no pain and suffering. Now it is available for any who want to take advantage of this technological advance, and for those who don't want to be a burden to society. No one is to be forced to take it, of course.

Hopefully, this scenario is unduly pessimistic, but it is a warning. For it is likely that the majority of those who would not want to "be a burden" would be older women. As caregivers and nurturers, women are socialized to sacrifice themselves for the good of the whole. So the following scene is not unimaginable: At the hospital bed an official is saying, "Mrs. Jones, your medical benefits have expired and I understand you are without personal resources. We are required to offer you a speedy release from your suffering." Mrs. Jones has been sick, poor and alone for 13 years. Her sense of self-worth is minimal. She may well accept that "speedy release" offered to her. But when she has no evident options, is that real self-determination?

Besides the concern about government pressures, there are worries about how to protect frail older people from the self-interests of their heirs. If "pulling the plug" becomes more and more acceptable, will there not be relatives who favor removal of life support systems not so much out of sympathy for the ill person as for an expected inheritance? Or if there is no inheritance, but relatives are paying the enormous costs of long term care, might not that be an incentive to bring matters to a close? This could be a problem with the durable power of attorney, of course. Courts examine--but sometimes not carefully enough--the self-interest of persons (including guardians) who are making decisions.

In fact, many of the concerns about life support systems have an economic basis. Would a government, concerned with the fact that 25% of Medicare expenditures cover costs in the last year of life, try to hasten the process to save money? Would a relative who makes decisions for a dying person do the same? Medical "advances" have made dying a very expensive process. While economic factors are often masked, in the long run they are too often the deciding ones.

PRINCIPLES TO WORK FOR

How do we then move forward through this minefield? Clearly, we have to make personal decisions for ourselves and explore the problems as a group. Before considering specific action, here are some principles to help provide clarity.

1. Move forward carefully, seeking the right to medical care without control by medical institutions. As the President's Commission stated: "Once someone realizes that the time and manner of death are substantially under the control of medical science, he or she wants to be protected against decisions that make death too easy and quick as well as from those that make it too agonizing and prolonged."[27] We must talk about control of our bodies without jeopardizing our right to adequate medical care. Health care to the end of our lives should be a right, not a trap.

2. In policy related to health care of the aged, the dollar sign must not be "the bottom line." Unfortunately, the question is seen as "What is the cheapest way to keep an old person alive?" -- if not in so many words, at least in practice. Even those proposing innovative alternatives to institutional care such as adult day care, hospice care, and Medicare reimbursement for home health care emphasize the cost savings in order to get support for their programs. These arguments are expedient in the short run but dangerous in the long run. The least expensive way of handling the last year of life is to end it. When it comes to care of persons who are dying, the "bottom line" must be compassion, not cost.

3. Informed consent is more than "signing a paper" at the hospital admission desk. It is a profound ethical and legal obligation of the entire medical profession. Health care professionals should improve patients' abilities to make decisions themselves and should promote understanding of the available treatment options.[28] Women particularly need to take a more active part in their own medical care so they feel more comfortable with making decisions when the time comes.

4. Society has a moral obligation to ensure that everyone has access to an adequate level of care and can obtain it without excessive burdens.[29] Because it is impossible for most people to pay for health care, especially at the end of life, the moral obligation to ensure equitable access rests with society as a whole. As the President's Commission stated, this obligation is particularly acute when health care is needed to sustain life itself. Society's obligation to ensure equitable access to care is a cogent answer to "bottom line" economic arguments.

5. Sanctity of human life is an underlying moral principle which should apply to all situations. Women need to take the lead in demystifying "heroic death," whether in warfare or another situation. To die for others is indeed the greatest sacrifice a person can make, but pressure to do so should not be used for narrow economic interests or political gain. Today's military technology demands use of other means of resolving conflicts, just as medical technology requires a new look at prolonging life.

6. Cost control in medicine should not be accomplished by restricting services needed by the aged and dying, but rather by more rational health care delivery. Less emphasis on technological innovation and more on providing basic care and reducing the profit motive for providers would accomplish more in the long run and help keep the Hippocratic oath intact.

7. Long term care of the chronically ill is today's greatest challenge to the health care community. Only through the development of options for treatment and palliative care, can there be a humane policy for helping people die with dignity. Essential missing elements are the willingness of society to pay for it, and new approaches to meet varied needs.

WHAT CAN BE DONE?

With these principles providing a long range vision of the future and fully aware of the contradictions and the dangers inherent in the subject, what immediate steps can be taken to move forward in this sensitive area?

A) Starting with ourselves

When individuals plan ahead for contingencies in their own lives, they not only lessen the risks for themselves, but they often have positive impact on public policy as well. For example, if a large number of persons take seriously the importance of preparing advanced directives in case they can no longer make medical decisions for themselves, they will want to make sure that these are going to be of use when the time comes. So they will push for legislation to support those documents.

At the present time living wills are the most widely used advanced statement of what a person would want, in case he or she can no longer make a decision on medical treatment. Everyone should prepare one and then make sure it is in the physician's chart.[30]

However, that is not enough to be certain one's wishes will be carried out. If you have someone you can trust and with whom you have discussed what you would want done in one situation or another, prepare a durable power of attorney as well. This document has advantages over the living will because it permits a person to designate a surrogate who is empowered to make decisions for the signer. The right of a person to designate someone else to make decisions in his or her behalf is well established in law. Of course if there is state legislation which clearly provides protection for medical practitioners they will be much more likely to abide by the surrogate's instructions.

What else can you do? At the suggestion of Concern for Dying and the Society for the Right to Die, hundreds of people have written to their local hospitals asking how their advance directives would be regarded if they become critically ill patients with no hope of recovery. Did the hospital have a policy to honor the instructions of the patient and the surrogate? Some hospitals answered that the inquiries had spurred the creation of a policy on living wills. As in most things, consumer action can stimulate institutions to act.

Further, you can encourage relatives, friends and especially parents to prepare advance directives. While it may be a difficult subject to broach, better sooner than later. Anyone about to enter a nursing home should be encouraged to express their wishes on possible future treatment. What would they want to have done? What would they find abhorrent?

Since this is a rapidly changing scene and state legislation varies, preparing an advance directive is not something one does and then forgets about. Like a will, this additional form of advanced planning should be made by every person (and especially older women) and reviewed periodically in light of changes both in the law and in one's personal circumstances.

However, as indicated earlier, these state laws authorizing living wills have problems, including definitions of terminal illness, restrictions on removal of nasogastric tubes and other limitations. The California Natural Death Act of 1976, the first in the nation, had such stringent requirements that its author chose to amend the durable power of attorney statute as an alternative means of strengthening the rights of the dying patient.[31] The result is a new section of the law, spelling out procedures and providing immunity to both the surrogate and physicians who act in compliance with the dying patient's wishes.

B) Legislation supporting advance directives

From the individual's viewpoint, having both a living will and a document designating a surrogate is the safest way to go. From the legislative viewpoint, amendments to state law covering durable powers of attorney will strengthen personal control of medical care at the end of life. They will be legally binding on physicians and apply to situations other than terminal illness.

As of this writing, thirty-five states and the District of Columbia have some form of legislation concerned with the "right to die." This may be an area where persons concerned about their own medical autonomy will find common ground with physicians, who on the whole would like some of the gray areas clarified. The durable power of attorney for health care, with legal backing through state legislation, would give physicians protection from prosecution when they withdraw life support systems at the direction of the surrogate.

Considering the public viewpoint as expressed in the Gallup and Harris polls, there should be broad support for such legislative efforts.

C) Guidelines and standards

Legislation is not the only way to make change. When an issue is "ripe," procedures and practices can be adjusted by public pressure. Writing to hospitals as suggested above is one means of getting action. Because of media attention to recent cases in New York state, Governor Mario Cuomo set up a Task Force on Life and the Law, because hospitals and doctors in that state had no uniform standard for letting patients die. A panel of lawyers, doctors, educators and clergy were charged to prepare such guidelines for consideration by the New York legislature.

Ethics committees--interdisciplinary bodies established to help make difficult decisions on care of patients--could assure that different perspectives are brought to bear when hard decisions must be made.

For example, in 1985 one-third of the beds in San Francisco General Hospital's intensive care unit were occupied by people in the process of dying. In one case, an 83-year old man with a ruptured esophagus, who also suffered from arthritis, Parkinson's Disease, a dislocated hip and senility, was rushed from a nursing home to the hospital. He was put in the intensive care unit where he languished for 50 days before being moved to a ward to die. His primary care doctor said, "I'm not deviating from a master plan of rules here, because there are no rules...my medical sense and my training have not given me the background or the right to decide who should live."[32] The resulting hospital bill of $122,579 fuels the argument that dying costs too much. Advocates hope that San Francisco General was forced by publicity to reconsider its policies regarding dying persons and develop guidelines, with primary consideration for the wishes of the patient.

All persons in the health care professions can, through their workplace and their professional organizations, urge the development of guidelines and standards in accord with the wishes of their patients.

Public education

It is one thing to provide legislation for a living will and durable power of attorney for health care and quite another to ensure that people use them. Only 50% of people who die have a will, even though wills are generally regarded as essential for responsible families. How much more difficult will it be to convince people that they might someday end up in a hospital in a comatose condition and would need someone to make life and death medical decisions for them? Nevertheless, there are steps that can encourage people to prepare the document. One target population is lawyers who make up wills. They could be encouraged to suggest to their clients that at the same time they prepare a will, they also prepare a living will and a durable power of attorney for health care. Of course this strategy assumes that the lawyers are themselves educated on this matter and recognize its importance.

A second target population for encouraging dissemination of advance directives is medical personnel. Once educated themselves they could develop unobtrusive and respectful methods for educating new patients and their families on the matter. Doctors and hospitals could have the documents available for their patients. Hospitals could develop mechanisms to ensure that all their personnel know that a patient has such a document and who the surrogate is. Charts could be marked, for example.[33] Individuals who have a surrogate or living will should discuss this with their physician, not only in their own interests but to raise the doctor's consciousness on the subject. The doctor could be encouraged to make other patients aware of the importance of the document.

In addition, organizations can contribute to public education by bringing the subject out in the open for general discussion, painful as the topic is. For example, in July 1985 the Older Women's League held a public forum on Capitol Hill, entitled: "Taking Charge of the End of Your Life." The purpose of the event was to stimulate dialogue among policy makers and national organizations about personal autonomy at the end of life through the use of advance directives. Other organizations and the media need to encourage as much public discussion of these issues as possible. Once the subject is out of the closet, we are in a better position to move forward despite the inherent contradictions and dangers.

Creating new alternatives for terminal care

When the final time comes, it is likely to be in a hospital. All too often death takes place in the emergency room or in the intensive care unit, the very worst places to die in peace, since they are set up on the premise that death is the enemy. Even nursing home patients are transferred to acute care facilities if there is any problem, including the big "problem" of dying, even though the patient may be ready to die. (On the other hand, many advocates are as concerned about undertreatment as overtreatment, especially in nursing home settings).

A serious effort to provide an alternative is the hospice movement mentioned earlier. Efforts should be made not only to extend the program but to remove some of the most restrictive regulations. Flexibility is the hallmark of effective human services. The hospice "movement" must not become the hospice "industry."

Nursing homes could become more like hospices for dying patients by adoption of the hospice philosophy and by an influx of funds. At present, however, all too many nursing homes provide neither a home setting nor much nursing. Many would be better named "nursing aides homes," since direct caregivers are rarely trained nurses. These aides must have more training and better pay to provide the kind of services needed. Since the majority are women, many of them older, upgrading of nurses aides improves both the work status of a grossly under-paid group of women and services to nursing home residents, also overwhelmingly female.

In regard to the end of life, a few nursing homes have "no transfer" orders on patients' charts, if this is their wish. Such a statement would say that in the event of a final illness, the patient would rather die at "home" (that is, the nursing home). Most nursing homes do not want to rock the medical care system boat. What is needed is a policy choice which would not make treatment a first priority, but rather the wishes and needs of the patient-resident, including letting the person stay at "home" (the nursing home), if he or she wishes.

Hospices need to be extended and made a more common alternative, available not only to the terminally ill, but also to elderly persons who are coming to the end of their lives in a normal fashion. Meanwhile other alternative arrangements need to be tried. Anything that can be done to further the development of compassionate alternatives to hospitals will

provide more choices for dying persons and their families, particularly if these options receive public funding and are therefore available to a wide constituency. This includes all aspects of long term care, as well as new ways of providing palliative care in hospitals, nursing homes and other institutions.[34]

On an individual basis, a person facing death will have a far better chance of staying in control to the end by staying out of a hospital if at all possible. However, planning to die at home assumes the availability of a caregiver who is ready, willing and able to provide the necessary support. And this raises a new problem. Will women caregivers have to take on that responsibility?

Conclusion

If any segment of the population can take the lead to brush aside the blocks to viewing death compassionately, it is older women. We are the "compassion experts," having been brought up with this trait. We have the most to lose if ways are not found to let us die in peace, in a place of our choice surrounded by as much comfort as possible. We want these things for ourselves and for those we love.

Death and dying need to be brought out into the open so we can preserve the values that should be preserved and mitigate the dangers that exist. Of course there are no easy solutions, but if we do not act, who will take the leadership? It is a matter of life and death.

August 1986

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[7]Op. Cit., p. 1229.

[8]Bartling v. Superior Court, 163 Cal. App. 3d 186 (1984).

[9]Barber V. Superior Court, 147 Cal. App. 3d 1006 (1983).

[10]Except in cases of pregnant women, or other situations when the "public interest" appears to conflict with the person's desire to refuse treatment.

[11]Conroy (note 7), p. 1222.

[12]See Resource listing, p. 22-23.

[13]Treatment (note 2), p. 153.

[14]Barbara Mishkin, in tape transcript for Taking Charge of the End of Your Life: Proceedings, Older Women's League, 1985).

[15]Cal Health and Safety Code, 7187(c). Reported in Legal Analysis of the Right to Die, Rita Ann Reimer, Congressional Research Service Report No. 85-130A, p.3.

[16]Ibid. 7187 (f).

[17]Analysis (note 16), pp. 6-7.

[18]Treatment, (note 2), p.29.

[19]Harris, (note 5).

[20]Conroy, (note 7), p. 1234.

[21]Conroy, (note 7), p. 1224.

[22]See Resource listing, p. 22.

[23]See Resource listing, p. 23.

[24]PL 99-272, Consolidated Omnibus Budget Reconciliation Act of 1985, enacted in April 1986, provided for an increase of $10.00 per day for hospice services.

[25]For a summary of opponents' views, see comments of Robert N. Brown in Taking Charge (note 14), p. 49-53.

[26]This viewpoint was stated clearly in the report of the 1981 White House Conference on Aging: "Old age is the payoff stage of life, when decisions made and patterns adopted earlier begin to produce dividends or extract their price." Final Report of the 1981 White House Conference on Aging, Vol. I, A National Policy on Aging, p. 98.

[27]Treatment (note 2), p. 23.

[28]Treatment (note 2), p. 3.

[29]Treatment (note 2), p. 27.

[30]For copies of the living will and specific information about the law in your state, contact Concern for Dying or Society for the Right to Die. See also: A Matter of Choice: Planning Ahead for Health Care Decisions, An Information Paper. (U.S. Senate Special Committee on Aging, forthcoming).

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ORGANIZATIONS

Concern for Dying, 250 W. 57th Street, New York, NY 10107. (212) 246-6962. Membership group, with numerous publications, including a newsletter. Promotes living will declarations; sponsors conferences.

Hastings Center: Institute of Society, Ethics and the Life Sciences, 360 Broadway, Hastings-on-Hudson, NY 10706. (914) 478-0500. Publishes Hastings Center Report, a bimonthly journal on biomedical issues.

Hemlock Society, P.O. Box 66218, Los Angeles, CA 90066. (213) 391-1871. Membership organization, publishes a quarterly newsletter, Hemlock Quarterly, and other publications. Some local chapters; sponsors conferences.

National Committee on the Treatment of Intractable Pain, P.O. Box 9553, Friendship Station, Washington, DC 20016. (301) 983-1710. Publishes a newsletter to increase public awareness of the problem of pain and to further education and research on its prevention and control.

National Hospice Organization. 1901 N. Ft. Meyer Drive, Rosslyn, VA 22209. (703) 243-5900. Membership organization for hospices and professionals in the field. Serves as a clearinghouse for information on hospices, helps local groups establish hospices, engages in advocacy. Publishes a newsletter and quarterly, directory of hospices, and other information about the issue.

Society for the Right to Die, 250 W. 57th Street, New York, NY 10107. (212) 246-6973. Publishes newsletter and information on legal changes affecting one's right to die with dignity. Promotes living will declarations.